



SUMMER 2012

VOLUME 23 ISSUE 4

WWW.SPINALCORD.AR.GOV

# Spinal Connection

## Mark Your Calendar: 2012 Miniconferences

ASCC will be sponsoring two Miniconferences this fall. Miniconferences offer folks who can't travel to little rock the opportunity to hear the latest in SCI. The first is scheduled on September 21st in Hot Springs the second is scheduled for September 28th in Jonesboro.

Each conference will feature Dr. Tom Kiser, ASCC Medical Director and Associate Professor in the Rehabilitation Medicine Department

at University of Arkansas for Medical Science and SCI team Physician at Baptist Health Rehabilitation Center in Little Rock. Other topics will be preventing secondary conditions, using assistive technology and recreational options and activities.

Miniconferences locations and programs will be finalized and registration forms will be available on the ASCC website in mid August. Clients in the regions of the conferences

will be mailed brochures with registration information in advance of the conferences. Others may contact our offices at 800-1459-1517 for a copy.

Registration will be \$10.00 for clients and family members and \$20 for health care and social service professionals. Scholarships will be available for clients and family members. So, mark your calendar and plan to attend!

## ASCC Surveys Accessible Parking Sites

Everyone knows that accessible parking is a problem. While most businesses have a designated space, it often does not meet the ADA guidelines. Often, the space is in use and frequently the person who is driving the vehicle does not appear to be a person with a disability.

Many Arkansans do not understand that having the plate or placard only meets half of the requirement of the law. In addition, the person to whom the plate was issued must be leaving the vehicle in order to legally use an accessible space.

The ASCC Accessibility Task Force has been meeting for over a year to look at solution to these problems. We decided to complete

a study to see for ourselves how accessible parking spaces in Arkansas were being used!

The Taskforce recruited over 40 volunteers who lived around the state of Arkansas to sit at various locations and assess whether there was a placard or plate in use and whether the person who left the car appeared to have a disability. The study was by observation only, and there was no confrontation made with any drivers or passengers.

The results were eye opening! In over 200 hours of observation at stores, government offices, banks restaurants and other locations at 51 sites around the state, we observed 1,328 vehicles enter accessible parking spaces:

- 38% had a legal placard and the person exiting the vehicle appeared to have a disability
- 39% had a legal placard and the person exiting the vehicle DID NOT appear to have a disability
- 19% had no visible plate or placard
- 4% were vehicles (cars and motorcycles) parked in the striped loading zone

Obviously, there is a lot of work to be done to improve enforcement of accessible parking in Arkansas!

Thanks to everyone who helped us conduct these surveys!

## SPINAL CONNECTION

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## With Thanks

Donations this quarter from:

**Danny Dudzik**  
**Richard Genereau**  
**Lynn Gerulski**  
**John Hachett**  
**Paula Mills**  
**Jim Tate**

ASCC accepts tax-deductible donations. Contributions are used to assist our clients through purchases of equipment and educational resources.

To make a contribution, please contact ASCC at **501-296-1788 / 1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission**  
**1501 N. University, Suite 470**  
**Little Rock, AR 72207**

## From the Director

I had the opportunity to attend the Annual Scientific Meeting of the American Spinal Injury Association recently. It is a great meeting where the 'best and brightest' in the field of spinal cord injury rehabilitation and research present their findings. I thought you might be interested in a few of the reports that I heard while I was there:

Fatigue is a significant problem for over half of those living with SCI. For about 9%, it is life altering. In a report on a research study of over 2,200 adults with SCI, conducted by Dr. James Krause, we learned that lack of sleep was not the primary factor for fatigue. People who got little or no exercise were 250% more likely to be fatigued. Those with poor eating habits were also more likely to suffer fatigue. Other risk factors that were associated with fatigue included use of prescription medication to treat pain, use of alcohol as well as race and severity of injury. You cannot change all of those things, but exercise, good nutrition and decreases in alcohol and medication use are things an individual can change, if fatigue is a problem.

Another interesting study was about Autonomic Dysreflexia (AD). Dr. Susan Harkema and her colleagues surveyed Emergency Medical Services (EMS) personnel such as paramedics and EMTs in 4 major cities in North America. Though 91% said they had encountered a person with SCI, 72% had never heard of autonomic dysreflexia and in a short quiz about best treatment, the average score was 31%. I think the take home message here is if you have had AD, you definitely want to carry an ASCC AD Medical Alert card (available from your Case Manager) or other articles to provide medical providers with the information they need!

Finally, we got results of the 2012 report from the National SCI Statistical Center. Dr. Yuying Chen reported that there are about 12,000 new cases of SCI each year, about 40 cases per million population. The average age at onset has increased to 41 years of age. About 80% of SCIs are male. Causes of SCI are changing, motor vehicle crashes are still the highest, but at 39%, followed by falls at 27% and gun shot wounds at 13%. Though 57% of those with SCI are working when injured, only 12% work a year later.

Finally, the cost of living with SCI is high, as we all know! Direct costs average about \$66,000 a year for paras and twice that for quads! You can see a copy of this report at [www.nscis.uab.edu](http://www.nscis.uab.edu).

Try to stay cool this summer!

*Cheryl L. Vines*

## Consumer Guide on Bladder Management

The Consortium for Spinal Cord Medicine developed a consumer guide in 2010 to explain bladder management options for people with spinal cord injuries (SCI).

*Bladder Management Following Spinal Cord Injury: What You Should Know* is distributed by Paralyzed Veterans of America (PVA). Written by medical experts, this publication offers guidance on successful methods of bladder management which best suit your life style and health care.

The consumer guide provides an

overview of the Urinary Tract System, discusses common bladder issues and concerns, bladder-emptying techniques, and medications.

The guide also describes different surgical procedures to assist with gaining more control over poorly functioning bladders and provides advice to those who are considering a bladder management program.

This guide is an excellent resource but you should talk with your physician before trying new procedures or making decisions regarding your bladder management routine.

The Arkansas Spinal Cord Commission obtained copies of the consumer guide and these are still available to ASCC clients.

Anyone who is interested in receiving a copy of the PVA guide should contact your Case Manager or Mary Jo Stanton via telephone at 1-800-459-1517 or via email at [maryjo.stanton@arkansas.gov](mailto:maryjo.stanton@arkansas.gov).

For those who have access to the internet, this PVA guide and others are available as a free download from the PVA website at <http://tinyurl.com/bladdermanagement>

## A Little Hidden GEM Known as the Alternative Financing Program

Once in a while, we find programs and services that are little hidden gems! It is amazing how you never hear of something until you need it. Many of you probably felt this same way when you first heard about the Arkansas Spinal Cord Commission.

The Alternative Financing Program (AFP) is a special program of the Arkansas Department of Career Education's Arkansas Rehabilitation Services Division. This program was established in 1997.

Career?... Education?... Rehabilitation?... The strange thing about this program is that it does NOT require a Career, Education, or Rehabilitation goal in order for you to qualify for the program. It is basically a LOAN program that provides individuals with disabilities low interest loans for the purchase of assistive technology.

What is assistive technology (AT)? It is any item, piece of equipment or product that is used to increase, maintain or improve functional capabilities of individuals with disabilities. It includes any device

or service that assist you at work, school, home or during leisure activities. It is designed to improve your quality of life. A variety of AT helps individuals with disabilities live more independent and productive lifestyles.

Some examples of AT that qualify under the AFP are the purchase of a wheelchair, used modified vehicles, vehicle lifts, home modifications and computer technology.

To qualify, you must be an Arkansas resident with a disability (physical or mental impairment) that substantially limits one or more major life activity. Verification of the disability and resulting limitations to a major life activity is required. Applicants must be age 18 or older or have a co-signer age 18 or older. You can qualify for this loan if you have a 550 credit score or higher. They do take into consideration your debt to income ratio to ensure you will be able to afford the payments on the loan. Some borrowers will require you to have a co-signer.

According to Michael Vickers, AFP

Program Manager, "There is no loan too small... we have loaned as small as \$200.00". The loan rate is currently as low as 3.75% fixed with no prepayment penalty clause. The terms of the loan are based on the "average lifespan" of the equipment/AT.

A good example of how this loan program works, as it pertains to ASCC clients, is if you need \$2000.00 to pay your insurance or Medicare copay for your new wheelchair. Let's say in general, the wheelchair should last you 4 or 5 years. If you met the criteria for the 3.75% fixed rate, your payments would be under \$45.00 per month over the length of the loan.

For most of us, every dollar is crucial in these economic times. BUT...What a little hidden GEM of a program this can be for individuals with disabilities! It is an affordable way to ensure you obtain the AT that will keep you as active and independent as possible. For more information on the AFP or to receive an application packet, call Mr. Vickers at 501-296-1600.

# Guillain-Barré Syndrome and the Influenza Vaccination



By Tom Kiser, M.D., ASCC Medical Director

I have been asked to discuss Guillain-Barré syndrome (GBS) because of the concern of the spinal cord community with its association to the influenza vaccination.

I have been a strong advocate of the influenza vaccination in all my patients because of the higher risk of influenza in susceptible populations, such as those with a spinal cord injury, and the even higher risk of pulmonary compromise in individuals with a spinal cord injury after influenza.

I get an influenza vaccination each year to decrease the risk of giving influenza to my patients and my own risk of contracting influenza. Last year the University of Arkansas for Medical Sciences started requiring all employees to get the vaccination.

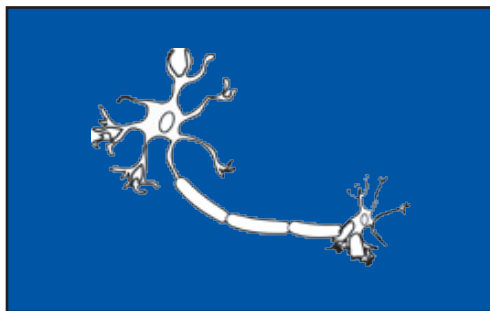
As I have discussed the vaccination with many patients over the years I have found their feelings run strong both for and against it, so I will give you information about GBS and influenza to help you make your own decision.

GBS was first described in 1916 and is the result of the immune system's being activated to attack the myelin sheath covering the peripheral nerves and nerve roots, causing a malfunction of nerve function. This is similar to the electrical short produced if the coating of an electrical wire is lost in the electrical system on your car. GBS is also called Acute Inflammatory Demyelinating Polyneuropathy (AIDP).

GBS develops in susceptible individuals after some infections and, in rare cases, after immunization. Sixty-seven percent of patients with GBS have a history of

a preceding viral infection, immunization, surgery or disease affecting the immune system. However forty three percent have no preceding signs of infection. Often diarrhea, due to gastroenteritis caused by bacteria called *Campylobacter jejuni*, can be the preceding infection that leads to GBS.

The clinical presentation of GBS is the acute onset of weakness, low tone and loss of reflexes. The weakness is progressive and usually starts in the legs and ascends to the torso and the arms. The brain stem and facial nerves can be affected. Respiratory failure is noted in up to 30% of cases within 1 to



2 weeks of onset, and the nadir (or most severe effect) of the disease is reached at about 4 weeks.

The medical management relies on the use of high-dose immunoglobulins (IVIG) or plasma exchange to reduce the duration of the paralysis and hopefully, the need for ventilation support. Steroid therapy has no proven efficacy. Rehabilitation management of GBS focuses on the prevention of contractures, skin breakdown, pneumonia, and depression. Recovery generally occurs within 3 to 6 months, but may take up to 12 to 18 months. Residual weakness, fatigue and sometimes pain are common but generally mild and manageable.

Epidemiological studies have



*ASCC Medical Director Tom Kiser, M.D.*

shown that, except for the 1976 US national immunization program against swine-origin influenza A, H1N1 subtype A/NJ/76, influenza vaccine has probably not caused GBS or, if it has, rates have been extremely low (less than one case per million vaccine recipients). By contrast, influenza-like illnesses seem to be relevant triggering events for GBS. However, the experiences from the 1976 swine flu vaccination program emphasize the importance for active and passive surveillance to monitor vaccine safety(1).

A literature review conducted in Japan could not draw any definite conclusions about a causal relationship between seasonal influenza vaccination and the Guillain-Barre syndrome. They concluded that the estimated benefits of seasonal influenza vaccination outweigh the reported risk of subsequent development of the Guillain-Barre syndrome(2).

Haber et al in a review article in 2009 found that the evidence for a causal association is strongest for the swine influenza vaccine that was used in 1976-77. Studies of influenza vaccines used in subsequent years, however, found small or no increased risk of GBS(3). In a review article from the Cochrane database on the Influenza Vaccination in the healthy population they noted a modest effect on time off work and no effect on hospital admissions or complication rates. Inactivated vaccines caused local reaction and an estimated 1.6

*Continued on page 5*



## Guillain-Barré Syndrome

*continued from page 4*

additional cases of Guillain-Barre Syndrome per million vaccinations. The authors concluded that the Influenza vaccine had a modest effect in reducing influenza symptoms and working days lost. There was no evidence that they affected complications, such as pneumonia, or transmission(4). When the Cochrane group looked at the evidence to vaccinate the elderly (65 years and older) (5) they found the available evidence to be of poor quality and concluded that it provided no guidance regarding the safety, efficacy or effectiveness of influenza vaccines for people aged 65 years or older. To resolve the uncertainty, they recommended that an adequately powered, publicly-funded, randomized, placebo controlled trial run over several seasons should be undertaken.

After reviewing the above data, it is evident that more research is required. In the meantime, you and I have to make our decisions based on the available evidence. As for me, I intend to keep getting my annual influenza vaccination, as I feel the benefits outweigh the risks.

1 Lehmann HC. Hartung HP. Kieseier BC. Hughes RA.

The Lancet Infectious Diseases. 10(9):643-51, 2010 Sep.

2 Kobayashi M. Takechi M. Kondo K. Ohfuji S. Fukushima W. Maeda A. Hirota Y.

Nippon Koshu Eisei Zasshi - Japanese Journal of Public Health. 57(8):605-11, 2010 Aug.

3 Haber P. Sejvar J. Mikaeloff Y. DeStefano F. Drug Safety. 32(4):309-23, 2009.

4 Vaccines for preventing influenza in healthy adults. Jefferson, Tom. Di Pietrantonj, Carlo. Rivetti, Alessandro. Bawazeer, Ghada A. AlAnsary, Lubna A. Ferroni, Eliana.

Cochrane Acute Respiratory Infections Group Cochrane Database of Systematic Reviews. 10, 2010.

5 Vaccines for preventing influenza in the elderly. Jefferson, Tom. Di Pietrantonj, Carlo. AlAnsary, Lubna A. Ferroni, Eliana. Thorning, Sarah. Thomas, Roger E.

Cochrane Acute Respiratory Infections Group Cochrane Database of Systematic Reviews. 6, 2010.

## Center Touts Leg and Arm Muscle Stimulation Bike

Victory Walk Inc., the non-profit spinal cord injury recovery center in Springdale, Ark., recently acquired a valued piece of high-tech equipment. Through a grant secured by State Representative Jon Wood, the center was able to purchase an arm attachment that greatly amplified the therapeutic value of its existing leg bike.

The combined RT300 Leg & Arm Bike helps clients with neurological disorders, including stroke victims, achieve their full physical potential. The equipment is manufactured by Restorative Therapies, the world's leading developer of Functional Electrical Stimulation (FES) powered systems.

"This equipment lets a person cycle securely and comfortably from their wheelchair or a standard chair," enthuses Lynda Lemke, Director of the center. Benefits of the RT300 vary from patient to patient but generally include reversal of muscle atrophy (loss of muscle mass); improved local cardio-vascular performance; increased range of motion and reduced muscle spasms. Dur-

ing leg cycling, up to ten muscle groups in one or both legs and the trunk can be stimulated. During arm cycling, the new computer and program allows the stimulation of up to ten muscle groups in one or both arms and the trunk. Stimulative therapy benefits come from actual operation of the muscles, which is not achieved in "range of motion" therapies.

In addition to typical leg and arm stimulation therapies, flexible programming of the FES apparatus can elicit stronger muscle contractions in therapy settings involving the standing frame, Total Gym and various floor exercises. According to Lynda, the effectiveness and versatility of the RT300 "exponentially increase benefits to all our clients."

Victory Walk Inc. is a 501-c-3 non-profit located at 1200 N. 40Th Street in Springdale, Ark. The center provides intense post-rehab Stimulative Therapy for clients with neurological disorders. For information please contact Lynda Lemke via telephone at 479-365-2600 or via email at [lynda@victorywalkinc.com](mailto:lynda@victorywalkinc.com).

## Accessible Hunting in Arkansas

If you enjoy hunting in Arkansas, now is the time to sign up for some of the exiting hunts scheduled for this fall and winter.

Southern Sportsmen Foundation is hosting it's ninth annual hunt on November 14-16th near Mineral Springs, AR. The deadline for applications is September 1st. If you are interested in more information or an application please visit <http://www.sharingtheoutdoors.com/> or contact Mike Cranford at 903-826-3318.

There are also a number of other accessible hunts taking place between October and January all across the state. The deadline for applications for applications for these hunts is August 15th. For a copy of the application visit <http://www.spinalcord.ar.gov/Resources/huntingapplication2012.pdf> or contact Toney LeQuieu at 479-356-1118.

If you are interested in one of the hunts please send in your applications as early as possible.

## Keep the Weight Off

Maintaining a healthy weight, especially with a spinal cord disability, is a challenge. Registered dietitian Vickeri Barton, RD, CD, from University of Washington Medical Center in Seattle, Washington has the following suggestions:

Allow plenty of time to plan and shop for your meals. Waiting until the last minute or when you're really hungry often results in overeating or choosing faster, less healthful meals. Thinking ahead and planning what you're going to eat - called "mindful eating" - helps maintain weight control.

Don't skip meals; this leads to snacking and overeating later.

Watch those portion sizes! Everything is oversized today, from the

average dinner plate to the size of a meal in a restaurant. Portions in restaurant meals are often equivalent to three meals! One serving of meat should be three ounces, or about the size of a deck of cards.

Use plate math. Divide up your plate: Half of what you eat should be vegetables, a quarter should be meat, or other protein, and a quarter should be grain.

Eat a variety of protein, grains, fruits and vegetables.

Choose low-fat, high fiber foods.

Read nutrition labels closely! Take note of the number of servings per package, because the calories and other nutrients are listed per serving. This is easy to miss. And

remember that foods labeled "low fat" can still be high in calories. See "Nutrition Label Reading Tips for Weight Management" at [http://sci.washington.edu/info/forums/reports/ADA\\_Label\\_Reading\\_Tips\\_for\\_Wt\\_Mgmt.pdf](http://sci.washington.edu/info/forums/reports/ADA_Label_Reading_Tips_for_Wt_Mgmt.pdf)

Watch your beverage calories. It's very easy to use up a large chunk of your daily calorie allotment in beverages. Drink water or sugar-free beverages if you are thirsty.

Weigh yourself as often as possible. It's hard to find scales that can take wheelchairs, but if you're only getting weighed once a year you won't know whether you're managing your weight. Try to find a place where you can weigh yourself at least once a month, such as a clinic or doctor's office.

## Vacations and Attractions in Arkansas

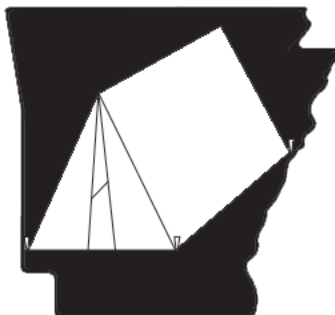
As summer begins, many people are preparing for family vacations or weekend retreats. While it's fun to travel to far off places, people often forget all of the fun opportunities that are available right here in their home state.

Arkansas, The Natural State, is well known for its natural beauty. With the abundant rivers, lakes, parks, mountains, gardens, caverns and trails there aren't many outdoor activities that Arkansas doesn't provide.

While not all activities are fully accessible, the state parks have been making great strides at updating facilities. If you wish to find out more information about accessible activities at Arkansas State Parks visit <http://www.arkansasstateparks.com/park-finder/search.aspx> or call 1-888-AT-PARKS.

Camping can be a very affordable

and fun activity for the entire family. With the temperature this summer already reaching triple digits you should be mindful and make sure to stay hydrated at all times. If the heat has you down be sure to check out some of the accessible lodges and cabins in Arkansas for the best of both worlds.



If you decide to adventure in to the great outdoors in Arkansas be sure to first check with the local city, county, or park authority to make sure there isn't a burn ban in effect – you want to stay safe and pre-

serve our natural state!

There are many other attractions and festivities to be seen across the state as well.

In north Arkansas there are several popular spots to choose from such as Mountain View and Eureka Springs. Mountain View is home to all things of yesteryear. The historic courthouse square is filled with crafts and you can often catch folk musicians putting on a show. Travel a few hours northwest of Mountain View and you enjoy the unique attractions of Eureka Springs such as The Great Passion Play or visit the 65 foot tall Christ of the Ozarks Statue.

If you would like an overview of some of the popular accessible attractions in Arkansas visit <http://www.arkansas.com/travel-tools/accessibility-information/accessible-to-all/>.



*Camper Conneth Johnson catches a catfish with help from a Centerpoint Energy volunteer at the fishing derby.*

## Spina Bifida Camp

Another year of camp has ended and 42 campers, ages 6 to 16, had a fun-filled week.

Friday morning, family members, friends and staff filled the Commons Building for the awards ceremony. Excitement grew as the campers piled into the auditorium. Each camper received an award.

Grace Johnson of Russellville was this year's Super Joe Outstanding Camper.

Spina Bifida Camp is a collaborative program supported by the Arkansas Spinal Cord Commission, Camp Aldersgate and Med-Camps of Arkansas.

If you missed Camp this year, and want to participate next year, be sure to look for details in our January 2013 newsletter, talk with your Case Manager, or contact Mary Jo Stanton at 501-296-1788 or 800-459-1517 or by e-mail at [maryjo.stanton@arkansas.gov](mailto:maryjo.stanton@arkansas.gov).

## Heat Has No Boundaries

Soaring temperatures cause an increase in the internal body temperature, which places greater demands upon the body's cooling system. There is a limit to how long a body can maintain a normal internal temperature of 98.6 degrees while in the sun.

An individual with tetraplegia or a high level of paraplegia, is unable to detect the increasing heat on their skin until they are in danger. If you witness signs of overheating, such as pale skin, confusion, and disorientation, especially with a person who has a spinal cord injury, get the person to the shade or indoors, seek help and proceed cooling the person off using cool wet wraps on the wrists and neck until help arrives.

It is easy to lose track of time while you are outside

having fun, so try these simple tips to stay cool.

1. Drink plenty of water; do not wait until you are thirsty sip on it continuously to avoid dehydration.
2. Wet a cloth and keep it around your neck.
3. Put a large cup of ice water (soda, lemonade) between your inner thighs. In the inner thighs are femoral arteries, which are some of the largest veins in the body that pump blood into the rest of the body. As you cool your blood, the rest of the body cools off as well.

Remember heat has no boundaries and will affect anyone outside enjoying the sun, so play it safe and enjoy the summer.

## Letter From the Editor

Have you ever come across some tidbit of information, some amazingly simple yet useful tool, or some way to perform some task that has made your life easier?

Sometimes even the simplest ideas can make a big impact on a person's day to day life and may be something no one else has considered.

If you have some helpful hint, "FYI", or hot topic I would love to hear from you. You may see your idea or information popping up in the next newsletter to help out many others!

Also feel free to send suggestions for topics for future articles that you would like to see in the Spinal Connection. We may not always be able to publish the topics requested but I will always take them in to consideration and let you know.

If you would like to contact me about the above or for any comments or suggestions feel free to send me an email at [jason.francois@arkansas.gov](mailto:jason.francois@arkansas.gov).

Jason Francis, Editor



# CLIENT SPOTLIGHT



**Erin Gildner of Bryant, AR**

**What is your level of injury or diagnosis?**  
*T-11/T-12 complete SCI.*

**Where do you work?**  
*University of Arkansas System Administration.*

**What type of job do you have?**  
*Associate for Administration.*

**How long have you worked at this job?**  
*Since February of 2011.*

**How did you locate your job?**  
*I found out about the opening for this position through my last job.*

**What type of state/federal benefits have you maintained?**  
*Medicare Part A.*

**What do you enjoy most about the job?**  
*Helping the Campuses with their projects and research analysis on policy updates and legislative research on capital construction.*

**What do you enjoy least about the job?**  
*Filing and scanning.*

**What accommodations does your employer provide?**  
*I received a new accessible desk. I also get to work from home when I'm sick or recovering from a hospital stay.*

**How do you benefit by being employeeed?**  
*I'm able to provide my family with insurance. I also make twice what I would make on SSDI. I get benefits and retirement... things I wouldn't have control of otherwise.*

**What made you decide to go back to work?**  
*My husband was in school and we needed the money. I knew I was capable of working. I didn't want to depend on government assistance.*

**How much support do your coworkers provide?**  
*They help me get stuff down since the cabinets are up high. Other than that they treat me like everybody else.*

**What are your future goals?**  
*I want to go back to Graduate School and get a Master's in Public Health.*

**What is the most positive benefit since starting work?**  
*Having control over my future... knowing I'm capable of everything I was before my injury.*

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